S. HRG. 98-466

# THE ROLE OF NURSING HOMES IN TODAY'S SOCIETY

## HEARING

BEFORE THE

## SPECIAL COMMITTEE ON AGING
## UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

FIRST SESSION

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**SIOUX FALLS, S. DAK.**

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AUGUST 29, 1983

Printed for the use of the Special Committee on Aging

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# THE ROLE OF NURSING HOMES IN TODAY'S SOCIETY

MONDAY, AUGUST 29, 1983

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
*Sioux Falls, S. Dak.*

The committee met, pursuant to notice, at 10 a.m., at Good Samaritan Village, Sioux Falls, S. Dak., Hon. Larry Pressler presiding.

Present: Senator Pressler.

Also present: Diane Swenson, legislative assistant to Senator Pressler.

## WELCOMING REMARKS BY CHARLES DINGLER, ADMINISTRATOR, GOOD SAMARITAN VILLAGE, SIOUX FALLS, S. DAK.

Mr. DINGLER. Charles Dingler is my name. I am currently serving as administrator of this facility. It is with great pleasure I introduce a very interesting person in the human aspect of our South Dakota area, Senator Larry Pressler.

## OPENING STATEMENT BY SENATOR LARRY PRESSLER, PRESIDING

Senator PRESSLER. I do want to start out by thanking Mr. and Mrs. Charles Dingler, administrators of this Good Samaritan Village for making this lovely facility available to us.

I would like to welcome all of you to this official hearing of the Senate Committee on Aging.

A transcript of this hearing will be made available to all members of the Senate Aging Committee, as well as my colleagues in the U.S. Senate. Written statements and comments are also welcome and may be submitted for the record.

After the hearing I will try to make myself available for as long as possible to visit with people. We also will put your summarized statements into the record.

The testimony we will hear from our distinguished witnesses today will focus on the role of the nursing home in an aging society. We will explore the problems our small town nursing homes face in conforming with Federal regulations and the burdensome paperwork these regulations create. We will also discuss the special problem of Alzheimer's disease patients; 13.2 percent of South Dakota's population is made up of people 65 years of age or older. As the chart behind me indicates (see table, next page), this figure has been increasing steadily.

POPULATION TRENDS IN SOUTH DAKOTA

| Year | Population | Older population (65+) | Percentage of elderly |
|---|---|---|---|
| 1910 | 583,888 | 19,288 | 3.3 |
| 1920 | 636,547 | 25,536 | 4.0 |
| 1930 | 692,849 | 36,915 | 5.3 |
| 1940 | 642,961 | 44,440 | 6.9 |
| 1950 | 649,710 | 55,300 | 8.5 |
| 1960 | 680,514 | 71,515 | 10.5 |
| 1970 | 665,507 | 80,484 | 12.1 |
| 1980 | 690,178 | 91,014 | 13.2 |
| 1990 [1] | 715,857 | 95,106 | 13.3 |
| 2000 [1] | 724,152 | 92,537 | 12.8 |

[1] Figures projected by South Dakota State Planning Bureau.

That 13.2 percent figure places South Dakota fifth in the country in percentage of senior citizens. Further, as the second chart indicates, the percentage of people in these higher age brackets will be increasing dramatically in the years to come. This increase will offer a challenge for all of us.

While a 1976 survey of nursing home residents indicates a high degree of satisfaction with care, as this chart illustrates, it is clear we must continue to examine ways to make nursing homes a better and less expensive alternative if we are to deal with the needs of our senior citizens.

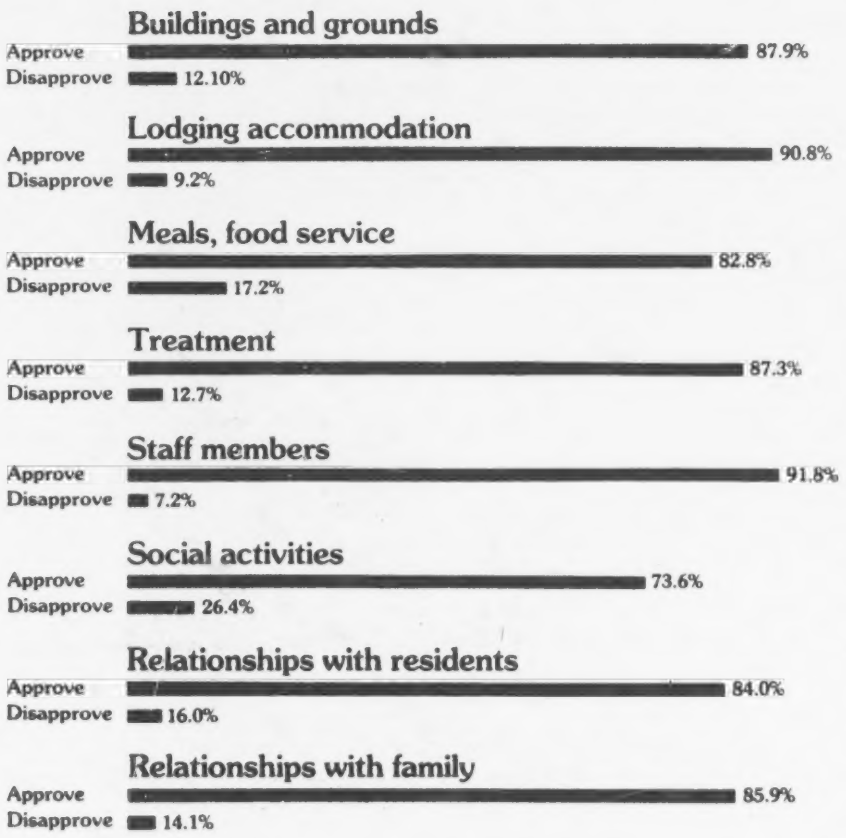
Let me illustrate this chart if I can do it for a minute here.

This is a rating of how nursing home consumers rate the care and services they received, and it illustrates the percentage of approval.

Buildings and grounds, 87.9 percent; lodging accommodation, 90.8 percent; meals, food, and service, 82.8 percent; and so forth, with perhaps the lowest approval rating being for social activities, at 73.6 percent.

The source of these ratings is the U.S. Census Bureau's 1976 Survey of Institutionalized Persons.

# How Do Nursing Home Consumers Rate the Care and Services They Receive?



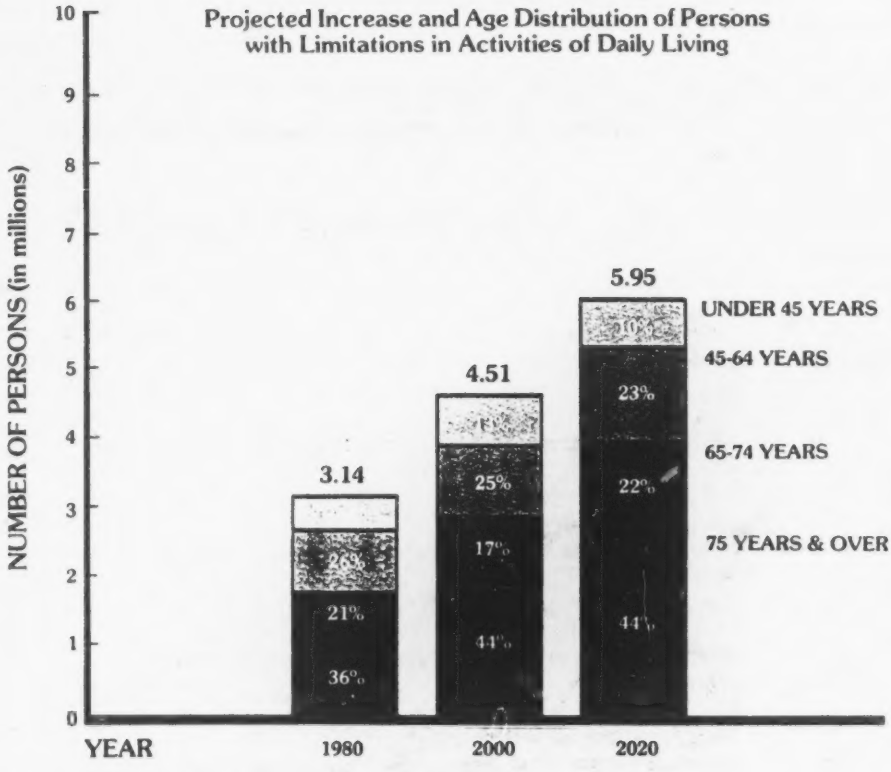

Source: U.S. Census Bureau, 1976 Survey of Institutionalized Persons

The chart I referred to earlier also shows the percentage of persons with limitations in activities in daily living.

The various percentages predicted for the year 2020 are: 75 years and over, 44 percent; 65 to 74 years, 22 percent; 45 to 64 years, 23 percent; and under 45 years, 10 percent.

Thus, the projected increase in age distribution of persons with limitations in activities of daily living is great. It should be noted that these are the groups which our nursing homes are dealing with. I just want to put those things into perspective here as we begin.

# Persons with Limitations in Activities of Daily Living




Source: National Center for Health Statistics

One of the key things for us to remember is that South Dakotans have always faced challenges like these head on, and will continue to do so.

People in South Dakota care for their elderly friends and relatives in the very best way they can. They do not shirk from responsibilities. Recently, I have been encouraging people to visit their area nursing homes for a few minutes on a Sunday afternoon. I know South Dakotans are excellent volunteers, and as I am sure that any of the residents of the Good Samaritan Village, or other homes who are present will attest, this small kindness means so very, very much.

Several examples of South Dakota's innovative ways of assisting the elderly will be discussed here. From the testimony of our first panel, we will learn the use of adult day care centers is increasing in South Dakota. In fact, we have centers operating in Huron, Scotland, Yankton, and Wakonda. Today we will learn about the opening of a new adult day care center at the Bergland Senior Center here in Sioux Falls.

In the area of Alzheimer's disease, which our second panel will cover, we will hear that there is a great need for additional research. Adequate means of diagnosis and treatment must be found.

However, we will also hear the success story of the Siouxland chapter of Alzheimer's Disease and Related Disorders Association which offers excellent support to the families of Alzheimer's patients.

With 1 of every 20 Americans between 65 and 75 years of age currently suffering from this disease, it is clear that there is a need, a vital need, for continued research.

During the debate on the continuing budget resolution last December, I introduced, and the Senate passed an amendment which would set aside $6.5 million for Alzheimer's research sponsored by the National Institute on Aging. Secretary Heckler of the Department of Health and Human Resources has created a task force to coordinate public and private research efforts. These are encouraging steps.

In addition to our research efforts, we must keep in mind the needs of those who currently suffer from Alzheimer's, as well as their families. This is a national problem and its solution will require a national effort.

The Federal Government has a role to play, but so do individuals and families and State and community agencies. I remain optimistic that together we can find help for the many Americans who suffer from this tragic ailment.

Alzheimer's disease has to be regarded as one of the most serious threats to this Nation's health and well-being. The disease already has stricken nearly 2 million persons, killing an estimated 120,000 each year. It is estimated that about one-half of all nursing home admissions in this country are victims of the disease. The costs of caring for these individuals and those at home now exceed $20 billion annually.

This is a bad situation and one which could grow much worse. We must take action to deal with this. The beginning steps in increased awareness which we will take today will play a part in meeting that tremendous challenge.

I want to thank all of the witnesses who have taken time to be with us today. If some of the witnesses have a lengthy statement, I would suggest that they summarize and place the balance of it in the record.

That being done, I also want to thank the people in the audience who have come here today. I look around and see many people I have met before, and visited with, and I hope to have a chance to talk to each of you individually, if that is possible afterward, but I thank you for being here, because your being here shows support, and it shows interest, and the level of interest in some of these problems is amazing.

As I hold my listening meetings around South Dakota, and as I have been active in various communities, I find that the level of interest is extremely high.

Let me call the first panel. I should first say that my wife Harriett is here today, and I don't know if she is in the room or has gone out to make a phone call. There she is. That is my wife Harriett

back there. They say an endangered species is a politician who forgets to introduce his wife.

At this time I will call the first panel. Dr. Hemming Oien, chairman of the South Dakota State Legislature Interim Health and Welfare Committee, Sioux Falls, S. Dak.; Dennis Callies, executive director of the South Dakota Health Care Association, Sioux Falls, S. Dak.; Lawrence Stahlecker, administrator, Good Samaritan Center, Wagner, S. Dak.; and Helen Noyes, Bergland Senior Center representative, Sioux Falls, S. Dak.

Let me say these are all outstanding South Dakotans and I have worked with all of them, and what they say here, not only today, but on other occasions, is most appreciated. I know that last year I had one of my senior citizen seminars in Wagner, and we really appreciated your hosting us there, Mr. Stahlecker. Also, we have been at the Bergland Senior Center many times and we appreciate that very much.

Let me say also that I have on my staff a senior citizen adviser who does casework on senior citizen problems, and that is Dick Macheak, who is here today and I should have him stand up. Dick, stand up and take a bow. Dick has been part time on my staff since I was in the House of Representatives. He specializes in problems of the elderly.

If you have a problem with social security, or feel that some aspect of it is incorrect, or some other problem, we cannot always make a change, but we can at least ask that your case be reviewed and that you be given fair treatment.

We also want to say that the agencies have a very difficult job, and very dedicated people, and a lot of times they turn out to be correct. We support them, so the people know what is available and what their rights are. Dick Macheak has been a specialist in that for many years, and does a great job. He is a retired executive from Northwestern Bell, and he has been a real good input in my staff from a management point of view, as well as on senior citizen issues.

I will call Dr. Oien as our first witness. He is chairman of the South Dakota State Legislature Interim Health and Welfare Committee and does a great job. We are very glad to have you here.

**STATEMENT OF DR. HEMMING OIEN, SIOUX FALLS, S. DAK., CHAIRMAN, SOUTH DAKOTA STATE LEGISLATURE INTERIM HEALTH AND WELFARE COMMITTEE**

Dr. OIEN. Thank you Senator Pressler, members of the panel, and members of the audience here today. I am going to briefly give you some of the problems that we are studying this summer in our interim health committee, and bring you up to date, and also I am going to give you a problem that you can help the elderly within this State, and help your Senator in Washington.

We are studying, this summer, the effects of the use of marihuana for cancer patients for the alleviation of pain. We decided that we would do nothing in that area, since there is a mechanism already in place for the oncologists or the tumor specialists to get marihuana. He can apply to the Federal Government for this permit, and so the marihuana is available through these types of

doctors. So, the people of South Dakota that wish to use this can do that.

Now, one of our biggest thrusts, of course, is to help the counties meet the needs of indigents' health care. These are people who just cannot afford or do not have the means to do this. We are looking for some avenue in which these costs can be met, perhaps through the medical needy aspect that we have not implemented in this State but is available from the Federal Government. We are looking at that.

I think that, cost shifting and the care that individual pays due to title XIX action, as we call it, is probably one of the most significant and most talked about areas that we hear year in and year out. And one of the responsibilities I think there is, that the Federal Government really is the—the Federal Government is the biggest single entity causing cost shifting, because they do not allow adequate funds for the expenses of the nursing home. They have what is called a bracket creep. It amounts to a slight shifting each year for the cost of the State of South Dakota, and it is less than 1 percent sometimes and sometimes it is more than that.

Denny, you can probably elaborate on these figures a little bit more when you get up here.

Those aspects, cost shifting, medicaid, medicare, and Blue Cross are the three main aspects of cost shifting. It is really considerable when you think of it.

We are trying to do something this year, and I work sometimes with Denny favorably and sometimes unfavorably, but as a member of the Appropriations Committee, as you know, we have to balance our budget, we do not like to do some of the things we do sometimes, but it comes in there.

We would like to introduce a little more flexibility into the way nursing homes are paid, of their internal use of the money they are paid on a daily basis, which would help them to a degree. So we are working on that aspect.

Senator Pressler, are you going to open this up to questions later?

Senator PRESSLER. I have some questions for you for the record. These are questions that the committee would probably appreciate answers to either now or in writing.

Could you elaborate on the flexibility and regulation which you are considering under medicaid, and how will this flexibility be helpful in providing cost-effective care? That is one question. If you can respond to that, maybe more in depth, for the committee record, but that is one area.

Also, the Congressional Budget Office has estimated that hospice care programs could save the medicaid program as much as $11 million in the second year of operation and $22 million in the third year.

What projections are you giving at the State level as far as the savings hospice care can provide?

Mr. OIEN. The hospice which has just been approved by the Federal Government, the figures I have—does everyone know what a hospice unit is? A hospice unit is an interim unit, it really replaces time in the hospital in a unit such as proposed by Good Samaritan, is to have a place where the terminally ill can live, and have mem-

bers of their family stay with them, they get 24-hour care as needed. The figure that Good Samaritan had projected was $75 a day. Now, if you figure the cost of the hospital at $165 a day, and that is quite—in Sioux Falls—that is realistic for a semiprivate room, then that would be quite a savings, and I think it is much more dignified to have a person live in a hospice unit rather than with his family surrounding him in the hospital.

The flexibility we were talking about involves the fact that the internal operation of each individual nursing home is somewhat different, their costs are different in different areas, and what we want to do is to put so much allotted for nursing care, so much for laundry, so much allotted for food, maintenance, so forth, that where they are efficient in one area and have a savings, that they could actually move that into another area to help defray some of the costs, because the costs are variable, and that is basically the answer to that question.

Senator PRESSLER. Thank you. At this point I will call on Dennis Callies. I might indicate that the questions we have for each witness are standard questions we are asking in each of our hearings throughout the country, and each witness may want to add more detail in writing later, but we are trying to get some cost comparisons, and so forth. So, at this point, Dennis, I will turn the microphone over to you for your statement.

**STATEMENT OF DENNIS A. CALLIES, SIOUX FALLS, S. DAK., EXECUTIVE DIRECTOR, SOUTH DAKOTA HEALTH CARE ASSOCIATION**

Mr. CALLIES. Thank you, Senator, ladies and gentlemen, and panel members.

I am going to deviate from my prepared remarks just a little bit, because of the place we are in, the setting we are in. Many of you people are not acquainted with this fine facility and the level of care that is offered here.

As you know, we have apartment buildings, supervised living level, we have intermediate care, and skilled care; those are the levels of care provided for nursing home residents here.

Now, we'll talk about alternative care, this facility can provide all the alternative care programs. They will offer hospice service if their certificate of need is approved by the State Department of Health.

I personally see no way that alternative care is an alternative to nursing homes. There will always be a need for nursing homes. To me, alternative care is another level of health service provided to the elderly in their own home. It is not going to keep the residents out of the nursing homes. If they need 24-hour nursing home care, that is where they are going to be, in a nursing home.

So with those comments, we will get into the reimbursement system within the State. As you know, we are on a so-called reasonable reimbursement system. The rates are determined by the State Department of Social Services. We have categories which we have ceilings on for the title XIX program. Also, there is a matching Federal fund to the reimbursement system provided by the Federal Government, and today in South Dakota, that figure is approxi-

mately 65 percent of every dollar spent on nursing homes. That is for the skilled and intermediate care, the supervised living rate is strictly a State-funded program on a 24-hour basis. The rate for supervised living is a little over $14 a day. That is 24-hour supervision, including meals, bathing, and so forth. You can see that rate is relatively low.

The reimbursement has to be improved in the State of South Dakota to allow the facilities to be competitive in maintaining professional staff and staff throughout the whole facility. They run 24 hours, provide food, showers, maintenance, housekeeping, laundry, activities, the whole program. And yet the reimbursement ceilings in some cases restricts the funds so that they cannot provide or maintain the professional staff needed to give the service, quality care to the residents they are caring for.

A speech pathologist, for instance, is not funded by a title XIX program, the only way to get this service funded is under medicare, if the facility is medicare approved, or by an outside contract. So there are limitations on that, also.

We would like to see and recommend that the State Health Department survey team plus the title XIX Department of Social Service medical review team be combined. We feel there is duplication in this service. It is expensive not only to the State but also to the facilities, taking time to work with these teams when they come in.

In addition to that, we feel the facilities, if they have a good track record, they should be able to do some self-surveying. Our national association has recently developed a quest for quality program, which is a self-survey program. I feel with that program, along with the health department, that a good survey can be done, assuring again the public and the residents that they are going to receive quality care.

Federal regulation is a burdensome, bureaucratic tie on the nursing homes, which in many cases, do nothing but duplicate affairs and make our professional staff into bookkeepers. We know our professional nurses spend many hours on recordkeeping, which is burdensome, which also takes their time away from being out on the floor delivering the care to the residents which they were educated and trained to do.

We have classification of residents which someone in Washington decided we needed, and we're going to call them skilled, intermediate, or supervised living. To me, this is another bureaucratic situation, and makes for the possibility of transferring residents from one facility to another, or town to town, because someone decides they are skilled or intermediate, and this level of care may not be available as they determine.

We are saying, let the facility provide the type of care and staff accordingly to the type of residents they care for. It does not make any difference whether they are skilled or intermediate, let them take care and provide the care as ordered by the resident's doctor.

I think also with that relaxation that you will see some savings in title XIX and health expenditures because the staff of the facility would be able to staff accordingly.

On the title XIX recertification, there is limitations of how often a patient/resident has to be certified as to the level of care needed.

We are saying if that has to be, then let us extend the requirements. Right now, intermediates have to be reviewed every 60 days. Let us change that to every 6 months. Also, the skill facilities, they are 30 days, let us change that to every 3 months. We have professional staff in these facilities that can determine if and when any health deterioration is shown.

In addition, we have the medical director, or we have the physician, attending physician, who will review and determine the health needs of the resident.

We are also asking that the Federal regulations allow more utilization of the physician extenders or assistants. Let them do more of the recertification work.

Medicare creates a problem for many, many of our elderly citizens in the State of South Dakota and nationwide. We would like to recommend the elimination of the 3-day hospitalization prior requirement to coming in to a skilled facility. Right now, in the State of South Dakota, we have six skilled facilities that are participating in a medicare program. The reason why, retroactive denial of payment to the facility after they have provided the service and again the burdensome amount of paperwork that medicare requires.

We are also asking they redefine the spell of illness. Right now, the bulk of the skilled and intermediate care facilities in the State of South Dakota cannot break a spell of illness for reestablishing utilization of medicare. The ruling is, that if a facility is staffed 1.6 hours of nursing care during a 24-hour period, they cannot break the spell of illness. If we have a resident that goes to the hospital because of some type of illness, he is transferred to a medicare-certified facility, and as their health deteriorates they have to stay there, they are utilizing up all their medicare days and, therefore, not ever be eligible the rest of their lifetime for the medicare program. The spell of illness should end when treatment ends for the given illness, not by the number of nursing hours.

Also, let's look at the utilization of the intermediate care facilities in the medicare program. That would help take some of the burden off the State dollars, also off the title XIX dollars. I would like to recommend also, that the nursing schools throughout the Nation incorporate more geriatric training in their programs, so that when these people are graduated from a school they have more of an idea of what kind of nursing they want to go into. They know about doctors' clinics, they know about hospitals, but they do not know anything about long-term care. They do not know what it is all about, how to provide it. They come into a facility, they may train for a couple or 3 weeks, a month or two, and decide long-term care is not their program. So they quit, it is costly to the facility to take its time of training them, and they have wasted "*x*" number of months of their time.

With these comments I will close, Senator, and if there are any questions later on I would be happy to answer them.

Senator PRESSLER. I do have two questions that I am sure the committee would appreciate being answered. You may want to answer them now and then expand it somewhat in written testimony.

The first question is: Could you give us further examples of how the Federal regulations have resulted in paperwork compliance rather than improved patient care?

The second question is: Under the new prospective payment plan for medicare, DRG's or diagnosed related groups that are to go into effect this October, how do you perceive this change in South Dakota health care will affect South Dakota's nursing homes?

I commend you on your comment on geriatric training and we will get into that in more detail later.

I will leave those questions and you can answer them now or make some written comments later.

Mr. CALLIES. I would like to make a few comments on the Federal regulations. Many of the consultants we are mandated to have should be evaluated. Discharge plannings is to me a ridiculous requirement. The residents are admitted to the facilities, the nursing home staff works with them, rehabilitates them. And if at any given time the staff, the nurses, the doctors determine these people can be discharged, they are discharged. I do not have the figures in the State of South Dakota, but I do know there is an awful lot of residents that are being discharged from the nursing homes going back into their own homes. Their improved health warrants it.

Senator, I would like to add to that, down the road, in writing, in regards to Federal regulations. The prospective reimbursement plan which is effective in the hospital area October 1, is a 4-year phase-in program, what we see happening with this is it is going to add cost to the nursing home. The people are going to be discharged from the hospital a lot faster, therefore, placing the more heavier care patients back into the nursing home, not only skilled but intermediate as well. Although this may be beneficial to the hospitals, I can see it adding, like I said, additional care and more costly care in the nursing homes.

I think we should go into a prospective reimbursement system for the nursing homes over the historical cost system we have right now.

Senator PRESSLER. Before calling our next witness, I must say that I have overlooked one brief introduction I meant in the beginning. We also have a senior citizen intern program in our office in Washington where we bring in one senior citizen a year for a period of time to work on legislation that I am working on, and amendments, and budgetary matters, and at least three of the past senior citizen interns are present.

Ruth Williams of Chester is here, would she stand up? She has been in our Washington office.

There is one back there, Carl Hanson of Parker is also here. He has been in our Washington office.

Also, Betty Atkins of Sioux Falls is here. Betty, where are you? There she is, right there.

Thank you all for being here.

I think they deserve a round of applause because they have done a great job.

I might add that some other senior citizen interns we have had, if any of them are here, we might—they might stand.

Is Rose Ewert here? She and her husband were senior citizen interns. He, I know, is deceased, but she is still very active and we talk to her a great deal.

Rose Bordeaux of St. Francis has been a senior citizen intern in our Washington office.

Cecil Munson of Sioux Falls. Is Cecil here? Yes, nice to see you.

We also have two senior citizen advisers in our Rapid City office.

I might also say that Diane Swenson has done a lot of the work preparing for this hearing. She works in my office as my liaison to the Committee on Aging. She has done a great job and I want to have her take a bow. Diane Swenson, who has done a lot of work.

Now, next we will hear from Lawrence Stahlecker, the administrator of the Good Samaritan Center in Wagner, one of the places I have visited where the concept of congregate housing is going forward.

We will be having our ninth senior citizen seminar in Lemmon to look at some of the West River problems, but Lawrence has done a great job as an administrator in Wagner, where last year's seminar was held. We look forward to his remarks.

## STATEMENT OF LAWRENCE STAHLECKER, ADMINISTRATOR, GOOD SAMARITAN CENTER, WAGNER, S. DAK.

Mr. STAHLECKER. Senator Pressler, the panel, and ladies and gentlemen, I may be repeating some items that have been mentioned before. The problems plaguing small town nursing homes. Inadequate funding leads to most all nursing home problems. Our aim is quality care. If we had the funds to properly train the people that are available to us in small towns, we feel that we could train these people to do a good job, with continuing education and a chance to better themselves. They will stay with us and we will have a lot less turnover in our staff in the small communities.

Also, the general public is demanding more rehabilitation services. The care is getting to be heavier and not lighter. We have more acutely ill residents than ever before because of the hospital cutbacks. They are released to us sooner than was once the case. Therefore, the small town nursing home is expected to give care to all levels of care. This puts a greater load and responsibility on the nursing home staff. Salarywise, it is very difficult to compete with private industry, and yet our staff in the nursing homes are expected to deliver things that many times the staff are not qualified to do, as we have not adequate funds to really train them as they should be trained.

We all have loved ones in our nursing home and we all want nothing less than the very best for them. Small towns also have a difficult time getting professionals because of locations and the wage market. A recent study has revealed that there is not a shortage of nurses, there are serious gaps of distribution.

We need support for nursing education, we need to give training, to interest people in the caring for the elderly. We need to provide more formal education and clinical experience in geriatric nursing, we need to look at health care facilities and educational units to collaborate with nursing education programs to develop programs,

to upgrade the knowledge and skills of the nursing aides, the L.P.N.'s, and the R.N.'s, who work directly with elderly people.

Medicare and medicaid policies should provide for these much needed educational programs. Day consultants in the rural areas is also a problem. Usually, the distance a consultant has to travel to get to a small facility in a small town is quite a distance to travel.

I would feel that it would also be more cost effective if the consultants in the dietary area would not have to call on a facility monthly. That perhaps this could be done on an every-other-month basis, as long as we have certified food service people. And also, that if problems of a serious nature arise they can also be contacted by telephone.

Recertification of residents in the nursing home really has no measurable impact on quality nursing care. It is a waste of the physician's time, the nursing home staff time, and a waste of the tax dollars. Medicaid residents in nursing homes are to be certified, proving that they need this type of service at least every 30 days in skilled and every 60 days in intermediate care. This recertification must be done by a doctor. It is accomplished either by mail or by the doctor's visits.

It is estimated that 850,000 ICF medicaid residents generate about 5.1 million recertifications in a year, at an estimated annual cost of $61 million. The whole problem is that certifications do not result in change of the level of care for residents in any significant way. A physician's visit to the nursing home for the purpose of recertification has really no effect on quality care. It only detracts from quality care of the residents, because of the paperwork associated with the recertification. Therefore, staff has less time to provide care which is their main function.

Health care in America should be a priority for the American people. The entire system of health care needs solutions, not costly regulations or cutbacks.

Senator PRESSLER. If you have finished, I have two questions for you, and again you can answer these now or submit additional written statements. Let me say first, that I think, Lawrence, you are running a great home and that your efforts are really great throughout your facility. In South Dakota, we are blessed by one thing that is a little different from that in our country's biggest cities, and that is that the employees and the people who run our nursing homes give very loving care. Sometimes in the big cities—and we will see that probably in New York City—some of the nursing homes become almost factories. That is not the case here. I think that Lawrence's work indicates that.

Could you further elaborate on the consultant requirements and give us an idea how this might be corrected to again provide quality care without unnecessary redtape and expense?

Second, I have learned that resident classification and certification has resulted in endless paperwork and often missed payments for our medicaid patients. How could these regulations be better written to accomplish our real goal, quality care for the patient?

You can answer either, or you can submit something in writing.

Mr. STAHLECKER. As for consultants, the reason I mentioned dietary consultant, we are all required to have a certified food service person employed in the facility that has to have at least a cer-

tain number of hours of education, and worked in long-term care for so many years. I feel that if we have a certified supervisor in our facility, that we do not need our consultant every month. They also take some of our time. We can have our own inservice which pertains strictly to our own facility and not all the facilities in general.

There are other consultants involved, such as social service and activity coordinator consultants. We are to have consultants for these people if they have not had 2 years of experience. But even an assistant could qualify if she has been in there long enough.

As far as regulations on certification and reclassification, I think this needs to be studied, Senator, I seriously do.

Senator PRESSLER. Thank you very much, Lawrence.

Next I will call Helen Noyes who will speak to us. She is the Bergland Senior Citizen Center representative here in Sioux Falls, and let me say that is a fine facility. I have been there many times and we are glad to have you here for your remarks.

## STATEMENT OF HELEN NOYES, REPRESENTING BERGLAND CENTER FOR SENIORS, SIOUX FALLS, S. DAK.

Ms. NOYES. I did not prepare a statement, partly because I have been on vacation, and partly because I could not understand how my part on this panel would fit on the role of the nursing home.

I take my cue from the gentleman who said there are no alternatives to nursing care, because I disagree. After working for 13 years with and for senior citizens and having become one, I feel there are numerous alternatives to expensive care in the nursing home. I have seen people who have had serious surgery, hip surgery and the like, who have gone into their own homes very early because of homemakers, senior companions, home delivery of meals on wheels, and other help in the home. I would like to see more people stay in their homes longer. I have seen people come into the senior citizens' center who have said they have gone to doctors for many years and they are perfectly healthy according to the doctor, and doctors have told people all you need is something to do. You have to keep busy because you are not ill. Some of these people have become so active they have not even visited the doctor in several years. In fact, back in 1975 when I was at the National Conference on Aged in Chicago, the late Mayor Daly said, "The answer to retirement is keeping busy." I did not have to go to Chicago to learn that. I am keeping busy, believe me.

I think that in 1961, with the White House Conference on Aging, the first Conference, we began to see a lot of retirement problems in a different light. We see retirement as just another segment in our lives. In 1971, we changed our goals considerably, and again in 1981, still changed our goals.

I think that there is a definite place for older people to have them in their own homes, and I am sure that some people have stayed in their own homes until the very day they died, and that is where they want to be. If you have to have around-the-clock help, it is a different situation, you need nursing homes and they are wonderful places. I have had my parents in nursing homes and I

know there will come a day when some people have to be in a nursing home.

However, there are cases as has been mentioned, where people have come out of the nursing home, and there are cases where people should probably never have been there in the first place. I feel that we must place more emphasis on senior centers, where people not only have recreation and companionship, which was the original goal, I guess, but a place for nutrition, opportunities to do volunteer work, RSVP—retired senior volunteer program—to get people out in the community so they feel they are still part of the community. It is very traumatic for a businessman or woman who has had an important position to suddenly find he is not needed any longer, but they have an opportunity to go out and do volunteer work in roles that sometimes were not their jobs, and often they are gloriously happy. Not only have senior citizens mushroomed, so have senior centers. At Bergland Center, we have a new program and are calling it senior daybreak because it is a break for those people who want to stay in their own homes but need some kind of supervision during the day, especially if they are living with a family, or alone, where they have to have medication, and so forth, and it is a break for the family if they are living with the family. We have the meal program which helps them physically, and companionship is just as important as nutrition, of course. If they need some rest during the day, medication, or other help, the day care program is another alternative to putting people in the nursing home. I still believe there are going to be a lot of people who are going to be able to stay in their own homes with a little more help from the community. Possibly we are going to have to have a little bit more local, and State, and Federal money going to these programs but it will be a saving in the long run.

As for myself, I want to keep working as long as I can. I think mandatory retirement was the worst thing that was ever invented. People used to work until they were tired of working. There are people yet who are working in their eighties and nineties, because they are in a job where they do not have to quit working. And when you have to quit, there has got to be an alternative, or you are going to be in a nursing home sooner than you think.

Thank you.

Senator PRESSLER. That was an excellent presentation.

We have two questions for you, Helen, and you can answer these now or later.

How do you think today's senior citizens view their long-term health care being provided? Are they hopeful about alternatives like adult day care services, home health service, hospice programs, and other new creative ideas making their later years happy years?

I think you probably already covered that.

Second, what has the response been to your adult day care center? Who should people contact if they are interested in learning more about this great center?

Ms. NOYES. I will answer the second one because that is the easiest one.

What has the response been to your adult day care center? Who should people contact? The response at first was very negative be-

cause the people at our center felt we were bringing in people who were incapacitated to the point they would be detrimental to our members. We will not integrate them into our center except in areas where they can be integrated. If they can take the congregate meal with our people, they will be allowed to do so. They may be able to participate in several programs.

As time goes on, I think our people will realize these participants will be very similar to themselves, except they are more frail and do need more supervision and a little more help. It is kind of hard to change a situation that has been going on for 13 years, and suddenly they think somebody is going to come in to do something they do not like. I think it is going to be very well accepted. I am beginning to feel more change in attitudes as the days go on and we are writing articles in our newspaper so that our members can get a little better picture of it. I have a few newspapers that I brought. They are going out in the mail today and I grabbed a few as I left the center. I did not bring any daybreak brochures, as you have some. I have been on vacation so I am a little bit disoriented today, which is another reason I did not have a prepared speech.

I feel we are going to have great success with our day care center and I believe that other panel members will make a few remarks on that.

How do you view the senior citizens viewing their health care provided today? I think they are scared to death. I think they are scared to death about becoming ill. They see costs of hospitals rising rapidly, they hear what it costs to go into a nursing home, and I think we must keep telling them, you know, this is not absolutely essential in your life. I think the best thing recently that has come about is our dwelling on wellness. I myself, in the last couple of years, am going back to exercising every day. I am on the go every day, and yet you need a certain amount of exercise for joints to stay healthy. I hear that every day. I have gone to annual meetings of the South Dakota Health Care Association, I have heard doctors talk, I have read articles which keep harping and harping, keep exercising. I remember my own mother saying, "I wish I had kept exercising." So, I think this emphasis on wellness is going to help us a great deal too.

Are they hopeful about alternatives? I think I more or less mentioned that. Home health care—I think people are beginning to realize there is help to be had. I think one of the problems about home health care is that people do not know what is available. We have people who come from out of town whose parents are having problems, and they are just lost and do not know what to do with them. They are afraid they will have to put them in the nursing home, but when they hear about the senior citizens center, they bring them down there and enroll them where they can get services, which include transportation. That is another area that is important for seniors, transportation. We also have a wellness center here in Sioux Falls, and there are others in Huron and Watertown. There are eight multipurpose centers in the State of South Dakota, and a multipurpose center provides not only recreation but meals, transportation, recreation, companionship, volunteer opportunities, and much more.

I feel that in a rural State such as South Dakota, a lot more people could stay in their rural areas if we would have multiple centers in a small town, or somewhere in the county, where they could be bused into the central location to get their meals, to have some companionship, and so forth. I think that would be a tremendous help to these people in the rural areas, because Sioux Falls is getting terribly crowded, apartments are getting higher and higher in cost and harder to come by, so I would like to see eventually more multipurpose centers in the smaller rural areas.

Hospice programs. I have heard nothing but good about hospice programs. One of our members, a longtime member, developed cancer and was in and out of the hospital. And the last year I believe it was, he was in his own home until the very end. His wife has done nothing but praise highly the hospice program. I've heard many such praises regarding help in keeping a terminally ill person with the family in their own homes.

There are other types of hospice programs too, that are excellent. I think we are all going to come up with new ideas. I think that if you have an opportunity to answer the questions, the questionnaires you receive, and you have any new, fresh ideas, I am sure Senator Pressler and a lot of our legislators will be tickled to death to get them.

Senator PRESSLER. Thank you for that excellent comment.

I want to thank this panel, and let me say that if some of you have thoughts or suggestions as we go along, we will take them in writing, and summarize them, and make them a part of the record. I would not underestimate your thoughts. As I go about holding listening meetings, I find a lot of commonsense from South Dakotans regarding Federal programs and things that might be occurring in your cities and towns.

That being said, I want to thank this panel and call forward the next panel, which will consist of Dr. David Bean, chairman and professor, University of South Dakota School of Medicine, Department of Psychiatry, administrator of South Dakota Human Services Center, director of South Dakota Division of Mental Health, Sioux Falls, S. Dak. Also Pat Brown, director of resident services, Good Samaritan Village, Sioux Falls, S. Dak. Louise Smith, director of staff development, Good Samaritan Center, Sioux Falls. And Lil Norlin, Siouxland chapter of Alzheimer's Disease and Related Disorders Association of Sioux Falls.

While they are being seated, let me say that some of the legislation that we will be considering in the near future in the U.S. Senate includes appropriations measures for health and human services, both authorizations and appropriations. Also, the earmarking of funds for Alzheimer's disease, or other diseases, for the National Institute on Aging, and a bill that I have introduced to set up a bipartisan commission to study the medicare problems.

We have the Social Security Commission, and Congressman Pepper, and I have a bill to set up a bipartisan commission on medicare, which is heading for financial disaster unless we take some steps.

Also, there is legislation pending regarding home health care, adult day care, and such programs as the adult day care center which will be opening in Sioux Falls.

So, there is a good deal of legislation and related amendments that are coming up this fall when we go back into session until early December.

With that, I would like to call upon Dr. David Bean, who has done such a good job, and also let me say that I want to give a salute to the University of South Dakota School of Medicine, which has brought so much to our State. The other day I had a meeting in which I discussed the Veterans Administration hospitals and how they worked with the school of medicine, I met with Dr. Quinn, and Dr. Hamm, and others. We are very lucky to have this institution and these people in our State, and they do a good job.

I will now call on Dr. David Bean, chairman and professor, University of South Dakota School of Medicine, Department of Psychiatry.

**STATEMENT OF DR. DAVID W. BEAN, SIOUX FALLS, S. DAK., CHAIRMAN AND PROFESSOR, DEPARTMENT OF PSYCHIATRY, SCHOOL OF MEDICINE, UNIVERSITY OF SOUTH DAKOTA; ADMINISTRATOR, SOUTH DAKOTA HUMAN SERVICES CENTER; DIRECTOR, SOUTH DAKOTA DIVISION OF MENTAL HEALTH**

Dr. BEAN. Senator Pressler, I want to thank you for the opportunity to speak at this hearing. I want to extend my welcome to all of the guests to this conference from the University of South Dakota School of Medicine. Senator Pressler asked me to speak specifically on the Alzheimer's disease syndrome and I will do that.

I have some lengthy comments that I will briefly present, lectures and sermons get old after 20 minutes and I think Diane said about 5 minutes would be sufficient.

Senator PRESSLER. Take as much time as you like.

Dr. BEAN. Alzheimer's disease is what we call in the medical field one of the organic dementias. A dementia is when the brain's cerebral cortex cells begin to deteriorate. In the old days, and I think in the common laymen's terms, we talked about dementias as senility. I think the thing to learn about Alzheimer's disease and the organic dementias of the elderly is these are not normal phenomena and it is not just aging. Aging is a different phenomenon and the diseases we will be talking about, Alzheimer's disease particularly, is a disease of the cerebral cortex that results in this dementing syndrome. It was originally identified in 1906 or 1907 by the German neuropatholcgist Alois Alzheimer.

What he found was a 55-year-old woman that began to show memory loss, loss of personal habits, and ability to perform in her everyday life and her occupational functioning; and after her death, they began to do some microscopic studies on the brain and found deteriorating findings in the brain. Since that time in medicine we have known Alzheimer's disease is one of the presenile and the senile dementia syndromes. Originally, we thought it was only a disease that occurred in the presenile or the before-65 age group, but our researchers identified this as a progressive phenomenon which occurs in some unfortunate victims in the early ages of their late adulthood, and others in the late ages of their adulthood.

The best description of Alzheimer's disease is the quote that I have heard from Charles Larioux of the Chicago Tribune who

wrote a rather interesting series of articles on the dementias and on Alzheimer's disease. I will just quote Mr. Larioux:

> If you are a taxpayer, it will savage your wallet; if you have got the disease, it will destroy your mind and cut your life expectancy by one-half; if someone you love gets it, it will break your heart.

The British Medical Journal has recently said that senile dementias are a "quiet epidemic" and characterized it as the major health problem of the 21st century. From a statistical standpoint the numbers are literally staggering. Of those people over 65, 5 to 6 percent will be showing some sort of a dementia syndrome. The vast majority of these are the Alzheimer's disease patients. In the United States, I think it is about 24.5 million people over 65 years of age and approximately 1 million of these will suffer a severe dementia and another 2 to 3 million will suffer a mild-to-moderate dementia. Most of these persons, perhaps 5 percent of the over-65 population, will have Alzheimer's disease. You can see it is a significant problem. Approximately one-half of our admissions to nursing homes are as a direct result of the senile dementias or Alzheimer's disease. One person has said the number of Alzheimer's disease victims in the United States equals approximately the population of Detroit, Mich., and Detroit is a vast city. And when you use these kinds of statistics you begin to understand just how significant a problem is this disease. Alzheimer's disease is additionally a physiologic killer. It is said that most people who have Alzheimer's disease are reasonably physically well, but in fact this is the fourth leading killer of the United States in adulthood, following heart disease, stroke, and cancer.

From an economic point of view, it is estimated there are $12.5 billion currently being spent on the care of these unfortunate victims, and it is estimated by the next 20 years that this sum will reach $20 billion.

The symptoms of Alzheimer's disease come on rather suddenly and mildly. A little bit of forgetfulness, a loss of the recent memory, inability to attend or concentrate in the daily activities, progressing on to severe and unremitting dementias, and severe and unremitting inabilities to care for one's self.

As the cerebral cortex goes, so does our socialization and our memory. Personality aberrations are common. The patient attempts to overcome his defects and may become irritable and cranky, progressing on to full-blown psychiatric illness that demands psychiatric hospitalization.

There are emotional effects on the family members as well as upon the patient. When a patient literally loses their mind, that causes a tremendous emotional burden on the family members, and it is even more so when that person who is "not normal any more" begins to forget the family members themselves. For those of you who have experienced this problem, as I have in my family, you will know that this is a problem of great significance.

Another side effect of the illness is the economic side effect. The economic costs of these problems make a moderate family almost economically deprived, and are a serious consideration to even the wealthy. It costs a great deal of money to take care of a patient in a nursing home. People have to give up their jobs to take care of

their family members in the early phases of this disease, which then, of course, puts them further in jeopardy from financial problems. When the family's resources are gone, the Government does take over. The State and Federal Governments do provide assistance through medicare-medicaid programs. But one of the problems that is really painful to me was reading of the husband who literally had to divorce his senile wife to gain some financial resources from the Government because he no longer had money to care for her.

What is the treatment for Alzheimer's disease? Unfortunately, there is little at this time. We have some techniques that have been developed, to aid this problem, such as self-help groups and the Alzheimer's and Related Disorders Association, which has become so prominent in the recent years. Miss Norlin will talk about the Siouxland chapter of that organization. But the hard, true fact of this matter is at this point in time, medical research does not have an effective treatment for this particular disease and the related disorders.

One of the helps I would just mention to you is a book entitled "The 36-Hour Day." It is an excellent book that gives very practical suggestions to family members and to patients themselves on how they can overcome some of the problems of dementias.

The end result, however, is not satisfactory, and that brings us to research. There are research efforts going on throughout the Nation in various medical centers and in the National Institute on Aging, the National Institute of Mental Health, and the National Institutes of Health. Unfortunately, there is not enough money going into these research efforts to come up with the answer to this disease. I think that just throwing money at a problem is not a good answer, but it should be understood that unless money for research in the origins of these diseases and the treatments of these diseases comes about, effective treatments will not come about. And so many people will continue to experience the suffering from these diseases unless further research moneys are forthcoming.

Senator Pressler's office asked me to comment on the mode of funding medical research. It is the difference between general research moneys or line item research money. It should be understood that in such diseases as complex as those affecting the brain that basic general research must be developed. We must find out just how that brain cell begins to develop, and grows, and deteriorates. So general research is very essential. But for more bounce for the research buck, I feel line item research is the way to go.

When you can focus your research dollars on such diseases as Alzheimer's disease, on heart disease, you develop a ground swell of public support, and a ground swell of understanding of the problems.

However, do not set up regulations or allow regulations to be set up that prohibit the general research that is so essential in these types of diseases.

What does the future hold? Well, we have faced these types of problems in medicine in the past with almost all the diseases that we have cured and are curing. Cancer was totally hopeless when I was a medical student back in 1956 and look at the things that we are doing now in cancer treatment that are just fantastic. I remem-

ber my little pediatric leukemic patient who died in 3 months. Today, leukemic children live to adulthood as a common result of cancer research. If there is more research money, and more attention to these diseases, I am certain we are going to have a much better outlook for the future for our citizens.

I guess that is all I would say at this point in time. Thank you, Senator Pressler, for the opportunity to speak on this problem.

[The prepared statement of Dr. Bean follows:]

PREPARED STATEMENT OF DR. DAVID W. BEAN

I. ALZHEIMER'S DISEASE: THE PROBLEM IN GENERAL

Alzheimer's disease is a chronic, progressive, disabling neurologic disease originally identified in 1906 by the German neuropathologist Alois Alzheimer. At that time, Dr. Alzheimer described a dementing disease of a middle-aged woman, upon the pathologic study of the brain, showed characteristic signs of neuritic plaques and neurofibulary tangles of the cerebral cortex and hippocampal areas of the brain. Since that time, Alzheimer's disease has been known to medicine as one of the major causes of "dementing" mental disorders.

Alzheimer's disease results in a progressive and oftentimes totally disabling mental disorder called a dementia (senility in laymen's terms) which results in personal, social, and economic disasters.

As Charles Laroux, of the Chicago Tribune stated, "If you are a taxpayer, it will savage your wallet; if you get the disease, it will destroy your mind and cut your life expectancy by one-half; if someone you love gets it, it will break your heart." Recently, the British Medical Journal in an editorial, described dementias as "the quiet epidemic" and characterized it as "the major public health problem of the 21st century."

In a statistical sense, the numbers are literally staggering. It is estimated that 5 to 6 percent of those persons in the United States over the age of 65 will develop senile dementia, with Alzheimer's disease being the major cause of those dementing problems. Of the 24.4 million adults in the United States estimated to be over 65, approximately 1 million of these people suffer from severe dementia, and another 2 to 3 million citizens suffer a mild to moderate degree of dementia. Approximately 1.2 to 1.5 million of these persons are experiencing the disease called Alzheimer's disease. It is further estimated that half of the admissions to nursing homes in the United States are attributable to dementias of the elderly, with Alzheimer's disease again being the largest component of those admission problems. Another way of looking at the problem is that the estimate of those patients currently affected by Alzheimer's disease in the United States closely approximates the population of Detroit, Mich.

Alzheimer's disease has also been described as the fourth leading "killer" of adults in the United States, following heart disease, cancer, and stroke as a major cause of death. Approximately 120,000 deaths per year is attributed either directly or indirectly to Alzheimer's disease. From an economic point of view, it is estimated at the present time $12.5 billion per year is expended in the treatment of dementias in the United States, with the costs of those treatments rising very rapidly toward the end of this century to at least $20 billion per annum of health care expenditure for this type of illness alone.

II. THE DEFINITION OF "DEMENTIAS"

Dementias are defined as a medical syndrome featuring deterioration of previously acquired intellectual abilities sufficiently severe enough to interfere with either or both social or occupational functioning. Impairment of memory, abstract thinking, and judgment are evident in fully developed cases. Defect of impulse control and personality change are also usually present. The clinical course of "dementias" may be progressive, static, or partly or fully remitting. In the case of the senile dementias such as Alzheimer's disease, these diseases are usually not remitting and are most frequently chronically progressive, and ultimately result in the demise of the individual either directly or indirectly secondary to the defect in brain function characteristic of this illness.

### III. SYMPTOMS OF THE ALZHEIMER'S DISEASE

Symptoms of Aizheimer's disease can occur in either the presenile (before the age of 65) or in the senile period of an adult person's life. The heralding symptoms are usually loss of recent memory and the ability to attend to, and concentrate upon, usual and mundane activities of daily life. These early signs progress into further deterioration in which there is loss of abstractive ability, disorientation, and loss of the abilities to intellectually function in a general and a specific sense in everyday life.

Personality aberrations are common which are a reflection both of the emotional distress that the patient feels as a result of the progressive illness, and as a result of the patient's attempt to, or inability to, control his or her behavior. Eventually, the individual becomes a "total care" problem in which basic body functions, such as eating and general body care have to be assumed by others. The progress of the disease may be relatively quick in the sense of a few years or prolonged for periods exceeding a decade.

### IV. "SIDE EFFECTS" OF ALZHEIMER'S DISEASE

The problems of Alzheimer's disease not only affect the individual whose "mind deteriorates" but, of course, add significant adverse emotional and economical problems to family members and to society as a whole. The emotional effects upon the family members are significant in that the previously normal loved one is no longer "normal" and with loss of memory, literally "forgets" his own family members and loved ones. The family member must tolerate the loss of themselves to the patient, which is particularly painful, but must also tolerate the patient's personality and behavioral aberrations that frequently develop and which can become quite severe and lead to the need for psychiatric hospitalization or nursing home care.

An additional family problem, which becomes significant to even the wealthy, is the tremendous economic burden of financially totally caring for an individual who has Alzheimer's disease. Family expenditures for home supervised care and for nursing home care are frequently extensive.

A further economic problem occurs when a working family member has to cease work to personally care for the individual thus bringing two persons, the patient and the family member, into significant economic jeopardy. To the persons of moderate means, this disease can literally devastate any personal or family savings until ultimately the family is reduced to economic destitution. At the point of family economic disaster, generally Federal and State government payments will intervene to provide for continuing nursing home and/or psychiatric hospital care for these individuals.

### V. TREATMENT

It still is true that effective treatments for the deteriorating brain cells such as those resulting from Alzheimer's disease are not yet available. While intensive research is ongoing in various medical centers and government agencies throughout the Nation, the problem still exists that there are no effective treatments for this disease. Ultimately, the disease process continues its downhill preset source which may be slowly insidious or may progress at a more rapid rate depending upon the individual affected.

There are, however, techniques that have been developed to lessen the disability, such as the making of lists to overcome memory loss, the development of legal guardianships to handle economic situations, identification bands for the patient, and the like. Unfortunately, at best these coping techniques only put off the inevitable downhill course of the disease.

There are other aids to families of Alzheimer's patients which have been developed, such as self-help discussion groups, information services and practical suggestions for helping patients. A good resource for identification of these aids is the Alzheimer's Disease and Related Disorders Association, 292 Madison Avenue, New York, N.Y. 10017. This association acts as a public interest group and a clearinghouse for information on Alzheimer's disease. Additionally, private organizations and government research institutes have developed information, handouts, and books on the dementias that provide practical information for both victims and their family members. An especially useful resource book for family members is the "36-Hour Day" by Mace and Robins which provides information and practical suggestions for family members concerning the problems of an Alzheimer's disease patient.

VI. RESEARCH EFFORTS

As mentioned previously, there are a number of national research efforts ongoing throughout the United States studying the dementias and particularly Alzheimer's disease. Unfortunately, the research dollars currently appropriated at this time are too few to yet permit medical scientists to develop understanding of the disease processes and effective treatments. While it is true that "just throwing money at a problem" does not always result in a solution, it is even more true that without effective amounts of research moneys being directed at problems such as Alzheimer's disease these problems will not be solved. These problems will not be solved in time for the proper prevention, resolution, and treatment of the millions of victims now present and those soon to be present in our society. More research moneys are desperately needed to expand current research effort in Alzheimer's and related diseases.

VII. MODE OF FUNDING OF MEDICAL RESEARCH

I am told that there has been some concern raised in previous congressional hearings as to whether Federal research moneys should be "general research" moneys or "line item" research moneys for the attack on illnesses such as Alzheimer's disease. Whether one directs research efforts in a general sense or in a line item sense, it must be understood that necessary basic research is always in part "general." Researchers rarely know what isolated bit of "general" research will bring forth new and progressive understandings and treatments of a specific disease. Line item research efforts on specific diseases must have as their foundation "general" research efforts to solve the problems of these specific diseases.

I personally prefer "line item" research funding efforts on medical illnesses because of the significant focus that can be brought forth in that manner to the specific disease. However, it must be understood that in these "line item" research efforts, "general research" efforts should not be prohibited but rather should be supported in the regulations funding the "line item" research.

VIII. WHAT DOES THE FUTURE HOLD

With the attention that Alzheimer's disease is beginning to receive both in the general public and in the Congress of these United States, I am certain that there will be forthcoming greater efforts and greater results in determining the nature of these diseases and in the finding of effective remedies for their causes and disabilities.

The real question that is presently raised to the Congress is how much of the gross national product of our United States will now be expended in the development of research on these problems that cause uncountable miseries to the victim and his or her family members. I humbly submit that while there are numerous problems that demand portions of our national expenditures the problem of the victims and family members of Alzheimer's related diseases is terribly significant and the research efforts toward the finding of the remedies for these problems are grossly insufficient to the need.

I strongly recommend to this congressional hearing and to the Congress of these United States that a greater financial effort should be made to find the causes and develop remedies for this tragic group of illnesses. I strongly support the increase in congressional funding for research efforts on Alzheimer's and related diseases.

Senator PRESSLER. Dr. Bean, I think you have covered all the questions that we had. One of the questions was, would you elaborate for the benefit of all of us, who are just learning about the disease, why diagnosis is so difficult? It is obvious this disease now ranks as the fourth leading killer. It must be a comprehensive and complex disease. I think you commented on cost. Your comments on line item and general research problems are most important to my colleagues and me.

I might explain that last session I had an amendment on the Senate floor to earmark certain types of funding for aging research. This is criticized sometimes in the Senate. They say we should lump sum and let the experts do the funding. I think good research is high risk research sometimes, but I think your com-

ments have already covered that question. I want you to know that I have found your comments most helpful and I am sure we are going to use them.

Could you elaborate on the areas of research, where it might be possible for us to find the answers for this ailment?

I think you have covered each of these, but do you have any further comments that you might want to add?

Dr. BEAN. Let me chat about the confusion in diagnosis. Basically the diagnosis is made on a neuropathologic examination. That means an examination of the brain tissue under the microscope. Quite frankly not very many people before death are terribly willing to have us go in and snip out a bit of the brain and look at it, so the diagnosis is particularly difficult.

We do it on a clinical basis, the development of what most people call the senility syndrome and the exclusion of other illnesses which might be causing a dementia. The problem of diagnosis is significant. I say my mother has Alzheimer's disease because she has followed the clinical syndrome quite well, but we have not been able to definitively diagnose mother's problem yet. And that is one of the problems that affect any of the emotional disorders such as schizophrenia or manic depressive disease, we have to use indirect means to develop our diagnoses.

Senator PRESSLER. Thank you very much. Next I will call Pat Brown.

## STATEMENT OF PATRICIA BROWN, DIRECTOR OF RESIDENT SERVICES, GOOD SAMARITAN VILLAGE, SIOUX FALLS, S. DAK.

Ms. BROWN. I would like to welcome everybody here to the Good Samaritan Village and please feel free to look around after the hearing is through. We would be glad to have you see what the village is all about.

I have been asked this morning to speak on the problems and concerns connected with Alzheimer's residents as we have observed them here at the village. We do have quite a few residents here at the village with the diagnosis as Alzheimer's. I think we are seeing this more and more within the last year or two.

Usually when a resident comes here to the village with Alzheimer's, we are seeing the residents that the family cannot cope with at home, for many, many reasons. I will go down through the list of some of the problems and concerns as we have observed. The first one I think that we really watch is the resident with Alzheimer's that becomes lost if they walk out into the hall from their room, they will look from one way to the other and are completely lost as far as which way to go or even to turn around and go back into their room. As you see, the village right now, you see that we have many doors. Our biggest concern is if they do get outside of the facility, it is very important that they do have some kind of identification on them, if they happen to walk down the block and do not know how to turn around and come back again. We cannot put locks on their doors, we do not want to put locks on our doors, we want them to feel free to come and go as they wish.

Another thing that we see is their speech problems, their inability to remember the word they want to say, or even to complete a

sentence. And to express themselves, their needs, and their concerns. Eventually we are seeing no speech at all.

Another thing is their difficulty with their attention span, concentration, and comprehension. Their inability to perform ordinary daily tasks, such as their own personal care. At first, it is a simple reminder of an act is usually sufficient, just to say it is time to get dressed now.

Then later, they need to be told specifically and repeatedly what to do. Still later, they do not respond to the verbal command, but will continue an action if it is initiated for them, such as if you put the comb in their hand, tell them to comb their hair and put their hand to their head.

Their ambulation. We are seeing that it is rigidity of their arms, legs, and torso, and they have unsteady gaits. Falling is our main concern. They cannot seem to sit still, they keep pushing themselves backward. We find with this that reclining chairs are very, very important for an Alzheimer resident. Very important to keep them walking for as long as possible. In other words, that means with each Alzheimer resident to walk that patient as much as possible throughout the day. Then eventually we are seeing they have to be restrained because of the chance of their falling or of them getting outside.

We see a personality change as we go along. They become very insecure, they do not like to be left alone. They become very paranoid; and what we really see helps with them, is they like to be touched. They like personal touching. They become disoriented to time, place, and the mood change. Normal failure of all memory is the eventuality.

Their eating habits. To begin with, they can have a fantastic appetite, they can eat breakfast and 5 minutes later say when are we going to eat. Then later become indifferent toward food and have to be reminded to eat throughout the whole meal. Then eventually they do not care whether they eat at all and they have to be assisted. This is where the nutritional assessment is very, very necessary.

Also I was asked to speak on hostility when it comes to the Alzheimer's. I have to say here at the village we have not experienced that. I think what we have seen is frustration and anxiety, but not hostility. Lil is going to speak a little bit later and she is going to speak on some nursing homes that would not take Alzheimer's. I have got to say that we have never refused an Alzheimer's patient.

When it comes to the family, they need support emotionally, it is very hard for them to watch somebody they love, their spouse, mother or father change completely from one person to the other, or to change roles they are not used to. They have fears and guilt feelings. They may become bewildered in attempting to cope with the personality change.

Another need I really have seen is the legal part. As the judgment and the reasoning of the person diminishes, they may need expert advice, the family should be advised as to the necessary arrangements, and steps to be taken when a person ultimately becomes incompetent.

Then there is always the time when they do have to go into a long-term health care facility, and we do have quite a few of them here in the Sioux Falls area and throughout South Dakota.

This is another thing, not too many people I know visit nursing homes unless they have the need or maybe a friend. And I think we all have to agree that long-term health care facilities have changed from what we used to know as nursing homes.

Training and staff. Louise is going to speak on this a little bit later. We have not attended too many workshops for the training of the staff on Alzheimer's. We have come up with quite a few things here at the village we would like to share with you what we feel is very, very important for the staff to know about. No. 1, as I said before, it is to keep them walking as long as possible. No. 2, is to protect them from physical injury, such as falls. Daily exercise is very, very important. Nutritional status is very important. Preserve mental functions, assessment, and evaluation of medication. Because really and truly they have not come up with the medication that will help. Provide regular social interaction, maintain self-esteem to involve them in activities of daily living. Structured environment, in other words the same thing day after day.

Prevent unnecessary translocation shock. Particular attention should be given to the use of nonverbal communication techniques, as well as verbal, to maintain effective communication problems with them.

Provide an ongoing support group for the family. That is very important. It is important to keep the family involved. We do care planning on each one of our residents here and it is important the family member is amongst them. Let them know what is going on.

Protect the patient from infection, maintain bowel and bladder elimination through routine consistent toileting, do not put a catheter in until it is necessary. We find this last one is the most important. It is love. A lot of patience, compassion, and a sense of humor can also be the most helpful.

We do have a beautiful Alzheimer's support group here in Sioux Falls. Lil is going to talk on that. Most of our residents' families do belong to this group. We have staff members here at the village who also attend these meetings.

Thank you very much.

Senator PRESSLER. Thank you.

Pat, your wonderful testimony covered the first question, so we will skip that one, but here is another.

Do you think Alzheimer's patients could benefit from a separate facility or the setting aside of a wing of a present facility in future plans? Would it be helpful to have specialized staff and more independent special supervised tasks for these patients? If you want to comment on it here you can, or you can submit something in writing.

Ms. BROWN. I can see a benefit of having a day care unit where they can walk around and not have to worry about them getting outside, where they are in a big room and there is staff that can watch them. As I said before, one-to-one personal touch is very important to these people. If we can have some type of setting like that, I think that would be really beneficial.

Thank you.

Senator PRESSLER. Next we shall call upon Louise Smith, director of staff development at the Good Samaritan Center here at Sioux Falls.

**STATEMENT OF LOUISE SMITH, DIRECTOR OF STAFF DEVELOPMENT, GOOD SAMARITAN CENTER, SIOUX FALLS, S. DAK.**

Ms. SMITH. I was asked to talk on the concerns of the geriatric nurse. I think it would be interesting to you to know that I have about 5 years experience in the geriatric field. My role of employment is with staff development. When the subject was raised to me, "what are the nurses' needs," I called on my many, many friends that are nurses, working in the geriatric field, and asked what their concerns were. They have all come up with the same answer, the lack of education for the geriatric field. The first panel talked about this, too.

There is a need for education in this particularly specialized area. Nurses go into nursing home work with their basic education, nurses of my age did not really have any geriatrics in their training. We had some psychiatric training, which is helpful in this area.

When you go to work in the nursing home, you have to rely upon your own experiences, you have to seek out your own educational materials, or you have to rely on workshops. As far as Alzheimer's is concerned, the majority of the resource materials in our nursing home were obtained through the association that Lil represents, we received almost our entire supply through that particular association.

As far as workshops are concerned, I think it should be mentioned that many of the facilities that handle workshops receive some Federal funding and this Federal funding is running out.

I have done some speaking with the area health care education programs here in the city and I understand that there is possibly about a year left before that funding will be gone and then the community will have to rely on their own funding. There are certainly other programs, the hospitals, the American Health Care Association, and the Good Samaritan Society, who put on workshops and these are really needed for further geriatric education.

Lil handed me a little card just before we came up here and it says,

> Bobbie Glaze, in a phone conversation, informed me that a new manual would soon be out on nursing care in the nursing homes for the Alzheimer's disease. Four representatives from the nursing home professionals are working to gather the preparation for this manual.

I can assure you that all the nurses that work in the nursing home area are going to be thrilled to have such a manual available to them.

Another thing that happens in the nurses' area of the nursing home situation is that the resident is often admitted with a diagnosis that is confusing. They might come in with a broad type of a diagnosis, such as organic brain syndrome, and it might take a while to find out what we are actually treating.

We talk about more research and more diagnosing, which is really essential for the nurses working with Alzheimer patients.

The general treatment for the Alzheimer person is a controlled environment, the use of restorative nursing, reality orientation, and drug therapy, these all take a lot of time and precise knowledge of the individual residents. Education of the staff is very, very important. In Sioux Falls, particularly, we have a high turnover of aides. In the smaller communities I do not think this is such a big problem, but here it is. It is difficult to train the frontline staff on how to handle the people with Alzheimer's. Not only does it take time, but it also takes a great deal of money to train staff in their roles.

Nurses also do a lot of consulting with the families. A lot of times the Alzheimer person will come into the nursing home and amazingly, with the controlled environment and the improved nutrition will, for a little while, look like they are getting better, but in reality they are just sort of buying some time and that will certainly be reverted in the near future.

The families have to be guided and counseled in this area. Frequently, it is the nurse who is doing this, it is really difficult if the nurse is not sure of her information on how to talk to these people, because they certainly do not want to give them any wrong information and give them false hopes.

I really feel strongly that there has to be some emphasis on the geriatric field itself, not just in Alzheimer's but the whole total geriatric field. I think that the schools of nursing and the schools of medicine should actually introduce this as a full field and spend a great deal of time on education in this area.

I have no more comments.

Senator PRESSLER. We thank you very much. One great advantage we do have in South Dakota in some of our smaller cities and towns is the quality of care due to the personnel. I do have some questions on the material which you have covered. You may answer now or you may wish to research more and submit a written statement.

I will just read these two questions which will be of help to the Aging Committee.

First, how can these same foundations, NIH, and NIA—National Institute for the Aging—do a better job of keeping you and other staffers, already working with our eldery, informed of the advances being made in work with Alzheimer's and other related diseases?

Second, in Washington, some groups are discussing the development of teaching nursing homes. Do you think this idea of providing National Insdtitute of Aging and National Institutes of Health grants to allow schools of nursing and medical schools to work with nursing homes to train staff is a good one?

Ms. SMITH. In answer to the last one, I not only think it is a good idea to provide grants for these schools, but I think it is a necessary thing. I think we have to do something to fund the programs so that the schools can at least provide a basic education for the care givers. I am not really sure how you could help keep the people responsible for education better informed. I imagine with more, well, just more communications, but a lot of times people do not take time to read, and sometimes I think that the material that is sent out should be in the forms of films, possibly tapes, something just a little bit more accessible to the very, very busy person who works in the nursing home. One of the problems with

educating the staff of the nursing home is simply getting them off the floor to attend the workshop. The other one is how to pay them once you do get them off. The people are eager to learn, and it would be nice if you could get some grants for the school of medicine.

I spoke with Coral Jauffer at Sioux Valley Hospital. She is the assistant head of the school of nursing, and she, too, expressed a need for a whole field of geriatrics. At Sioux Valley School of Nursing, geriatrics is covered briefly in the medical-surgical units.

Senator PRESSLER. Thank you. Next I will call on Lil Norlin, the Siouxland chapter of Alzheimer's Disease and Related Disorders Association here in Sioux Falls. Lil, thank you for being with us today.

**STATEMENT OF LILLIAN NORLIN, REPRESENTING SIOUXLAND CHAPTER, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, SIOUX FALLS, S. DAK.**

Mrs. NORLIN. Before I begin my testimony, I would like to share with you a quotation from the "50-Plus" August 1983 publication "Good Medicine," by Dr. William A. Nolen. This was helpful to me, and perhaps it will be of help to some of you today:

> Remember that although Alzheimer's is a devastating disease, it is not so common that we need live in dread of it. If your memory for names seems to be slipping, if you're misplacing your glasses more often than you once did, or if, as occasionally happens to me, you're 50 pages into a mystery novel before you suddenly realize you've already read the book, don't panic. As we get older, our memories aren't exactly what they once were. The explanation I favor is the more memories we have crowded into our brain cells, the longer it takes to sort out and retrieve them. Forgetting your wedding anniversary doesn't mean you have Alzheimer's. It just means you're in trouble at home.

That helps me. My brother who lives in California has Alzheimer's disease. When I was informed by his wife that his illness had been diagnosed at the Scripps Institute in La Jolla, Calif., I asked what the treatment would be. It was incomprehensible to me when she answered, "There is no known treatment or medication." I thought there must be something to arrest the illness.

My sister who is a nurse in Portland, Oreg., who had cared for Alzheimer patients, urged me to visit this dear brother before the disease would progress to the point where he would not know me. I did go to California in November 1980, and spent 10 days with my brother and family. My sister-in-law had reached a point of anxiety and exhaustion, physically and emotionally. When I arrived at the airport, my brother seemed genuinely happy to see me. We went to a restaurant, and for the first time I noticed how his wife had to take him by the hand, lead him to the restroom, then wait to bring him back to our table.

It was difficult, so many unspoken thoughts. Relationships seemed heavy with fear of the future. My time was spent going for long walks with my brother. He could not go alone, because several times he had become lost and the police would bring him home.

While I was there, I was his constant companion during the day. My sister-in-law told me she just escaped and left Ben with me, knowing he would be cared for in a loving way. I would ask him to write the names of our brothers and sisters and our parents, I

would spell the names for him. Sometimes he would not know how to write a letter of the alphabet. He would fold up the paper and put it in his shirt pocket and say, "I do not want to lose this, I need to keep it. Please help me with this tomorrow."

When I returned to Sioux Falls, I wanted to learn more about this devastating disease; I heard about Bobbie Glaze and wrote to her immediately, and this was the beginning of our support group in Sioux Falls and surrounding area.

Bobbie Glaze was one of four people to appear before Senator Thomas Eagleton's Senate subcommittee HEW appropriations hearing on July 15, 1980, in Washington, D.C. I have copies of her testimony available today for those of you who would like to read all of it.[1] With her permission and suggestion I will quote a few lines from her statement:

> I would like to share with you the concerns of the family struggling with Alzheimer's disease. I feel I can best relate this to you by my own personal tragedy, not to exploit what happened to our family, but because it is typical of thousands of families who may be crying silently for help. My husband was forced to retire in 1970. I excused, guided, and denied this was happening. I found part-time employment, but each day it was more difficult to be away from him as he became more confused.

She continued:

> We left our home and friends of 32 years and moved to the city where my husband was given complete neurological testing. I was given the diagnosis in the hospital waiting room filled with people. The doctor said, "Your husband has Alzheimer's disease, a progressive, irreversible brain deterioration for which there is no known cause or treatment. That's the way it is, you will have to go on from there." He excused himself and left to see another patient. I was given no explanation of what Alzheimer's disease is, what to expect, how I might learn to cope, nor was I directed to someone who might be able to direct me in the monumental problems ahead.
>
> His company of 25 years chose to terminate all of his benefits, disability, pension, insurance, because of this early retirement.

Bobbie visited 20 nursing homes in 1 day and finally found one that would take him. After 3 months she received a call that he had become violent and that the nursing home refused to keep him, even overnight.

When you read all her testimony you will understand the great heartbreak she went through before she began to seek out others who were experiencing the very real tragedy of not knowing to whom they could turn for help. Today we are thankful and blessed that one person, Bobbie Glaze, was willing to find some answers for her family and then to go on, contacting and counseling, founding a network of family support groups all over the United States.

She hoped to be present at the hearing today, but her doctor scheduled major surgery for her this very day. She is in the hospital today, the surgery will be tomorrow, a followup of heart bypass surgery a few months ago. I would ask that we remember her in our prayers for healing and good health in the days to come.

The Mental Health Association of the Sioux Empire assisted us in contacting individuals and nursing homes where there were Alzheimer patients, and the first meeting of the support group was held November 4, 1981. Eleven people were present at the meeting.

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[1] See appendix, item 1.

Today we have 110 families who have been represented at our meetings and new members come to each monthly meeting.

The goals of the Alzheimer support group include support for research in the diagnoses and therapies, and causes and cures, and most importantly, aid for families, sponsorship of educational forums for both lay and professional people. Most of all, we offer help in any manner when needed by those who have the disease, and their families. The Siouxland chapter of ADRDA is affiliated with the Senior Citizens Service, Inc., in Sioux Falls. We do, however, maintain a separate entity. Workshops have been cosponsored with GATE—Gerentology Association for Training and Education—which is a part of the education department of Senior Citizens Services.

Senior daybreak, an adult care program of Senior Citizens Service, will be helpful for family members as well as care providers. This program will be available for a few hours each day or all day Monday through Friday from 7:30 a.m. to 5:30 p.m. October 1 is the day scheduled for the opening. This service will give to the family of a patient or the care giver a few hours of freedom to work or other activities.

Beginning this month, our chapter members are included in the mailing of the senior citizens newspaper. This publication will have news of our chapter activities, time of meetings, and so forth, and also the topics to be discussed and shared, such as medical help, legal matters, nursing homes, and so forth. There are approximately 2,700 subscribers to this paper, so there will be much more exposure and information to the public about our support service.

Last year, Senator Pressler was a cosponsor of the Senate bill to proclaim the week of Thanksgiving as Alzheimer Awareness Week; we contacted our Governor, and he joined with many others in proclaiming November 21–27 as National Alzheimer Awareness Week; we also contacted our mayor, and the proclamation was issued for Sioux Falls.

It is our hope and prayer that our Siouxland chapter will be of help to the many families who may hear the doctor say, "Your husband, wife, sister, brother, parent has Alzheimer's disease."

I like the statement, when we are faced with the enormous decision of how to provide the best care for a loved one, we need to make that decision as wisely as possible. Then you need to adjust to that decision. The moment of absolute certainty never arrives.

Senator PRESSLER. That was a wonderful presentation. Let me ask you, there are three questions here which would be helpful to the Aging Committee which you can answer now or submit in writing.

What can people who may not be related to an Alzheimer victim do to help you and other family members who suffer from that tragic illness?

Second, how can family members of Alzheimer's patients get in touch with your organization in order to gain the benefits of your wonderful assistance?

You have already answered that one. I hope the beginning of an awareness week will help bring about that important first step. I guess just the first two of them, if you have a comment on either of them.

Mrs. NORLIN. How can family members get in touch with our organization? We do have brochures available with the names of contact people. There are brochures available today, and you may call on any of the people who are listed on that brochure for information.

Senator PRESSLER. Thank you very much. I think all of our witnesses deserve a round of applause.

That concludes our last panel of witnesses. They are all busy people, believe me. I know from firsthand experience that both panels are very hard-working, dedicated South Dakotans, and what they have said will be considered carefully.

Let me say that there are so many people here in this audience who should be introduced. I see directors of many of our nursing homes from towns and small cities from throughout the State here whom I recognize and have worked with. I would like to introduce all of you, but for lack of time, since the home here needs to serve their lunch at some point, we will have to be out of here so that they can proceed with their normal activities.

I would also like to note that Bobbie Glaze, who is a founder of the national Alzheimer's support group, was from South Dakota. She now lives in Minnesota, and would have come if not for heart surgery, as you said. Lil did talk about her and I wanted to say that because I know many of you know her. Copies of her testimony are available and her testimony will be made a part of the record.[1]

There are a number of other messages that we received from around the State, and calls, there are a number of people that want to see me afterward.

Let me say we will set up a table in the front here so we are out of the way for the residents. And those of you who have individual casework may come up and talk to my caseworker, Dick Macheak, and Diane Swenson, as well as Kent Scribner.

By the way, I should introduce Kent Scribner back there. Kent is one of the persons on my staff here in Sioux Falls. I am going to give a toll-free number out now and that number will reach Kent or his secretary. Also Mary Pat Bierle from our Washington office is here. We do have a toll-free number and I am going to give that out now. Our toll-free number in South Dakota is 1-800-952-3591.

I would also like to—I should also introduce Eileen Devick and Dr. Devick, who practices medicine both here and in Colton. These individuals have been very active in the Alzheimer's support group. Is Eileen or Dr. Devick here? There they are.

Would all the members of the Siouxland chapter of ADRDA please stand? Would they all stand, as a request from Mrs. Devick?

The toll-free number is 1-800-952-3591.

With that I am going to conclude this hearing by again thanking our witnesses. I would like to visit with as many of you as possible.

Thank you very much. And I thank the Good Samaritan Village for their fine hospitality.

Thank you.

[Whereupon, the committee recessed, to reconvene, subject to the call of the Chair.]

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[1] See appendix, item 1.

# APPENDIX

## MATERIAL RELATED TO HEARING

### ITEM 1. STATEMENT OF MRS. BOBBIE GLAZE BEFORE THE U.S. SENATE COMMITTEE ON APPROPRIATIONS, JULY 15, 1980; SUBMITTED BY LIL NORLIN

I would like to share with you the concerns of the family struggling with Alzheimer's disease. I feel I can best relate this to you by my own personal tragedy, not to exploit what happened to our family, but because it is typical of thousands of families who may be crying silently for help. I can tell you that it is like a funeral that never ends. My husband was a handsome, vital, athletic man, a civic leader, a public speaker, a highly respected businessman. He was administrative vice president of his company. He is now a statistic. He is permanently hospitalized, not knowing his family or speaking a word in the past 4 years. He requires total care as the physical deterioration takes its toll. I have a husband, but I speak of him in the past tense. I am not a divorcee, I am not a widow, but where do I fit?

I began noticing eccentricities, withdrawal from society, disinterest, lack of communication about 12 years ago. In 1970, he was forced to retire. I excused, guided, and denied that this was happening. I found part-time employment, but each day it was more difficult to be away from him as he became more confused. We dipped into our savings, were managing on very little income, losing everything we had. I finally admitted we needed help. We had no neurologists in our area of South Dakota, so a daughter persuaded us to come to Minneapolis where she could lend a hand. I decided to uproot (my husband could no longer make decisions). We left our home and friends of 32 years and moved to the city. There my husband was given complete neurological testing. I was given the diagnosis in a hospital waiting room filled with people. The doctor said, "Your husband has Alzheimer's disease, a progressive, irreversible brain deterioration, for which there is no known cause nor treatment. That's the way it is. You'll have to go on from there." He excused himself and left to see another patient. I have never seen that doctor again. I was given no explanation of what Alzheimer's disease is, what to expect, how I might learn to cope, nor was I directed to someone who might be able to direct me in the monumental problems ahead.

I was in a strange city, and I was not free to find employment. I tried work situations that might provide rent-free housing, but even that was impossible for me alone. We moved five times in 18 months, by necessity. That is, I moved. He came with me. We lived in an ever-diminishing world. His company of 25 years chose to terminate all of his benefits (disability, pension, insurance) because of this "early retirement." I was advised by an attorney not to fight it. I had moved to a different State, and the company had it own lawyers who could interpret the language the way they choose.

I was unaware of Veterans Administration assistance, and my husband could not communicate that information. I had accumulated living expenses, hospital costs, relocating costs, legal expenses, until we had no reserve. In this unreal world, I felt no sense of belonging. How could one explain this to strangers, and there were often embarrassing situations. People usually turned away. With the 24-hour vigil, I became totally exhausted—physically and emotionally. I felt I must be prepared for any emergency, night or day. It became frightening, living with this stranger who might push me, or twist my arm, or throw things at the television. The loving, gentle husband I once knew was no longer there.

This became an obsession with our entire family. I knew that we simply could not live that way any longer. We needed a care facility that could provide the necessary custodial care. We visited 20 nursing homes in 1 day, and finally found one that would take him. He was admitted the next day. The heavy guilt that the family

endures is indescribable when this step is necessary at such an early age. We question if we are "copping out." I also wondered how long I could manage the costs, for insurance and medicare neither one covers this problem. I inquired of medical assistance and was told my car was too new for me to qualify. My husband stayed in the nursing home nearly 3 months, when I received a call that he had become violent and they refused to keep him, even overnight. In my opinion, they panicked because of lack of training. They did not know how to care for this kind of patient. Most nursing homes are not equipped or staffed to handle this. At any rate, they sent him to a private hospital where he remained for 6 days before I could convince the hospital personnel to check his chart which read, "This man has no insurance, no medicare (he wasn't old enough). In an emergency call the Veterans Administration hospital." They did, and he was admitted. Fortunately, he remains there. But many of our veterans, even career servicemen are being turned away because they are suffering from an "untreatable" disease and there must be room for the "treatable" patients.

After my husband's admission to a permanent facility, and realizing this meant a lifetime, I came home to my very small apartment feeling a despair that is impossible to put into words. I was suddenly alone and desolate. I do not wish to sound overly dramatic, but I am attempting to state facts so that you may better understand the effects of Alzheimer's disease on our families.

As for myself, I was becoming a nonperson and realized that my thinking must be turned around. My children were caring and supporting, again a blessing, for not all families find this to be true—some simply cannot deal with it and walk away. Acceptance is probably the most difficult step for our families, and there are thousands of us. For a long time we look for improvement and for things to get better. This is not true with Alzheimer's disease. The condition only worsens. We need guidance and research methods of helping these families find appropriate medical professionals who are knowledgeable about this unique problem that is not a "mental illness" but is indeed a physical condition.

We need assistance with the appropriate type of care as the disease progresses, whether it is day care, respite care, home care, or long-term care. One individual cannot survive very long when dealing with this around the clock. We must find ways to provide care facilities for our people who have no place to go. We need direction in business matters, for we must plan ahead when the afflicted individual is declared incompetent and will be unable to sign documents of any kind. The remaining spouse is usually the one who is the responsible party and may be untrained in such matters. Legal affairs may require attention, especially if there is property involved. The very real tragedy is for the younger family who is faced with the disease that will continue on for a period of many years. There are often young children who will need to be educated and cared for. There are many variables in patients, and the duration of the illness varies also. Physical deterioration is usually a determining factor. In our family you will recall it has been at least 12 years.

Education for the whole world is a top priority. We need to use every resource possible so that all will know what this strange word, Alzheimer's, is about. The general public needs to know, but most importantly the medical community needs to know. In the beginning, I found it incredible that physicians and other medical professionals were not knowledgeable about Alzheimer's disease. It is indeed a happy surprise when we find some who are informed.

We have been advised to divorce, and some have. Some lose their homes, and most material things, as I have. We have already lost a loved one in this slow devastating process that diminishes one to a shell that simply breathes. We can do nothing for that victim at this time. Research is the hope for the future. We can help ourselves and do much to help others. This is the reason for my involvement today. I made a choice of helping drowning families in order that they might avoid some of the pitfalls I experienced. There was no one there when our family needed such a lift.

Our families have lost, but we choose to continue! Perhaps our greatest loss is our spirit for we have been degraded to a point of "begging for help" when we are already shattered.

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## ITEM 2. STATEMENT OF GERALD SPAWN, LAKE ANDES, S. DAK.

My name is Gerald Spawn. I'm from Lake Andes, S. Dak., representing the Lake Andes Health Care Center. And we have recently become aware of a problem that I think you should personally be very interested in, Senator Pressler. And that's the fact that in your nonimpacted areas—where health care is for a smaller number of

people than in your larger cities, and so forth, where the testimony was mainly concerned with in this hearing so far—that in these small areas there's a definite drive that's been given to the social services department.

And we found this out as an absolute statement from a caseworker clear up to the office of the Governor, that things were being done this way, that the legislature has instructed the social services agencies to keep people out of the nursing homes at all costs. Do whatever you can to keep people out of the nursing homes. Use one of these other programs that they have found feasible—which is a good government term—they found feasible because there was a need in South Dakota for home care, extended hospital care, the swing-bed retirement centers, adult foster care, adult day care, and so forth. They're all good programs.

But for one of these caseworkers in a small town to justify his job and show that he's worth his salt, he is putting everybody, whether they require 24-hour supervision or what kind of care they need, he's putting them with a home care worker. And as a result we have had one title XIX patient put into our home through our social services office in the last 2 years from Charles Mix County. We have received some from Gregory County. They evidently have a little different kind of staff over there that is more interested in why these programs were instituted in the first place, which was for the best interest of the patient, the best interests of the patient's loved ones, the best interests for existing health care, which are the nursing homes that satisfy the certificate of need when they were built, and also the taxpayer that expects a dollar for the dollar he's spending.

And with this home care, we find that 120 hours is the magic number. In one quarter, 120 hours is the maximum that is cost efficient for the home care program. If that patient were put into a nursing home instead of this day care that is getting this 120 hours in a quarter—that's 1 hour a day, by unskilled personnel by the way—that it costs between $2,400 and $2,500 for that care for 3 months.

Then you can put a figure according to that, I think, by dividing that by 120 to come up with an hour cost. That's $20 an hour for 1 hour of care a day by unskilled help to take care of somebody that needs around-the-clock potentially. For $6 or $8 more a day, they can have 24-hour care by skilled personnel. Now that doesn't sound very cost effective to me, that the taxpayers are getting their money's worth paying that close to what it would cost for skilled people to take care of this patient for that 3 months' time.

We've also been told by the social services department that when some family has finally come to their wit's end, they can't take care of their loved one anymore, they've tried, they cannot do it, they've finally talked their mother, or father, or whoever, into the fact that to get the proper care that they need that they should be in a nursing home. And that person doesn't really want to go, they want to stay in their house yet, but they finally talk them into it. And they can't afford to privately pay for them in this home, so they go to the social services office. And they've finally talked them into it, they're all sitting in a room, and in 10 seconds, a social worker sits there and says, "Do you really think you need to be in a nursing home? Don't you think that if you stayed in your own home and we sent somebody up there to care for you in your house that you'd be a lot happier?" Boy, that's just what she wanted to hear, because she didn't want to go anyway. And she winds up getting less care than she got before. And the family is at their wit's end, they can't do it anymore. But a home care worker is supposed to do it with 1 hour a day? Keep that lady from falling down in the middle of the night? Burning herself on the stove? Falling down and breaking a hip? Not being found for 2 days maybe? It doesn't make sense, and it doesn't make sense to the taxpayers if they find cut that this kind of instruction is being given by our legislators.

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ITEM 3. LETTER FROM LORA A. DEWALD, RRA, DIRECTOR, SIOUX FALLS, S. DAK., RURAL AREA HEALTH EDUCATION CENTER, TO SENATOR LARRY PRESSLER, DATED SEPTEMBER 1, 1983

DEAR SENATOR PRESSLER: I was present at the hearing for the Senate Aging Committee which was held at the Good Samaritan Village in Sioux Falls, S. Dak., on August 29, 1983.

Professionally, I am a registered record administrator—RRA—who has worked in hospitals and consulted in six different nursing homes as a medical record consultant for a number of years. Presently I am a center director for the Sioux Falls Rural Area Health Education Center—AHEC—which is a private, nonprofit corporation funded by a Federal grant through the South Dakota School of Medicine. Our

chief function is to provide continuing education for the health professionals in the rural areas of South Dakota.

My comments come in three parts.

*1. Certification and recertification of resident's level of care by their attending physicians.*—In my opinion, this is strictly a paperwork function that creates problems of documentations as well as deficiencies for the nursing home that are not warranted because the physician controls when he signs it. When this form was eliminated in the hospital setting, medical care did not deteriorate because of it.

*2. Requirements for consultants in certain departments in the nursing homes.*—I seemed to hear two things from the administration that spoke. One, reduce the numbers of consultant visit requirements and two, make more continuing education available in our facilities. Consultants are excellent resources for continuing education if they are used appropriately! They also are responsible for keeping the department they consult in updated. My experience as a consultant has proven that consultant visits prompt department personnel to better performance because, "someone will check the work." Depending on personnel, a lapse in consultant visits is demonstrated by lower performance standards. This is not true in all nursing homes or with all personnel.

*3. Continuing education.*—Limited dollars and many miles make it very difficult for nursing homes to keep their personnel updated. The AHEC funds have been an excellent source of dollars to provide quality continuing education in South Dakota and many times right in the nursing home itself. Last calendar year, the Sioux Falls AHEC provided 28 programs for hospitals and nursing homes. The maximum cost to a facility who sent four persons to each program (112 persons total) was $1,852 ($16 per person per program) for registration fees. A real deal! This funding is being eliminated as of October 1984, and South Dakota nursing home care will be affected.

I strongly recommend the elimination of the certification and recertification requirements.

I strongly support the use of consultants in facilities that do not have the size and resources to hire professional staff.

I strongly support some method of Federal support for continuing education for the health care professional.

Sincerely,

LORA A. DE WALD,
*RRA, Center Director.*

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ITEM 4. LETTER FROM WAYNE MUTH, VICE PRESIDENT FOR LONG-TERM CARE, BRADY MEMORIAL HOME, MITCHELL, S. DAK., TO SENATOR LARRY PRESSLER, DATED SEPTEMBER 1, 1983

DEAR SENATOR PRESSLER: I was in the audience at your recent Aging Committee hearing at the Good Samaritan Village in Sioux Falls. Thank you for the invitation to communicate my thoughts to you on some of the issues discussed at that meeting.

My interest in providing health care services to the elderly is both as a provider and a consumer. I have been employed in long-term care administration for 16 years, and members of our family are elderly consumers of health care services.

I presently work for the Presentation Sisters of Aberdeen, as their vice president for long-term care. My employment experiences have given me a closeup view of the delivery system which has evolved in this country. I do not like much of what I see. I'll get back to this later, but first I'd like to comment on some of the issues discussed in Sioux Falls.

EXPENSIVE NURSING HOME CARE

This statement or similar statements were made several times. I realize that quality care does cost, but the question should be is value received. I believe it is. Appropriate care received in a South Dakota nursing home is perhaps one of the best bargains our society has ever received, for example, 24-hour skilled nursing care is reimbursed at approximately $36 maximum per day by the medicaid program. This service includes all the essentials of life. Even in South Dakota, more can be spent for a motel room. Nursing home costs certainly compare favorably with the "new" hospice rates being quoted, and of course with daily hospital costs.

I find it strange that one of the selling points of hospice has been the cost savings that will occur. The savings estimates you quoted may or may not occur, but why isn't the same logic applied to the long-term care segment for our system? Long-

term care saves funds in the same manner that has helped "sell" hospice funding, but we have never been recognized for this accomplishment.

Less expensive nursing home care was mentioned as a goal of our elected leadership in Washington. The only way to accomplish this is for our society to decide our elders are entitled to less than a dignified life. Individuals who truly need inpatient services will cost more to care for, not less. The DRG program will intensify the trend we have seen for years. Namely, our admissions come primarily from the hospital, and our clients come to us at a very high level of need. This translates into more expensive not less expensive care.

ALTERNATIVE SERVICES

This phrase is meant to describe day care, home health, congregate living, respite care, etc. These services are essential and must become a part of our nation's health care delivery system. They are, however, not an alternative to inpatient services when that service is appropriate. We must stop selling them as a viable alternative, but rather as services that can be provided when appropriate.

Senator, we are not serving our elders by continually using their fears of the nursing home service to promote other services. They are all important, and I might add, all will continue to cost our society, if we believe in a quality life for our parents, and someday for ourselves.

Long-term care providers can and should have an integral part in providing other than inpatient services. We are, after all, the experts in providing for the needs of the elderly and disabled. Our facilities in Aberdeen and Mitchell provide the following: (1) SNF and ICF inpatient service; (2) congregate housing; (3) independant living; (4) adult day health care; (5) respite nursing care; and (6) community outreach clinics.

We are providing appropriate services at several levels, but really have not been encouraged by the government to do so. There are no reimbursement systems in place for services provided other than the inpatient services. People whose needs could be met in day care or congregate housing, for instance may, therefore, seek admission to the nursing home if they lack personal funds.

HOSPICE CARE

The hospice concept is admirable, and seeks to meet the many needs of a terminal patient and his family. The concept is really not new however. The modern nursing home with its dedicated staff has been using this concept of total care of client and family for years. The main difference is that society has asked us to accomplish a great deal with minimum resources. Many of us in long-term care are, therefore, skeptical of the bandwagon which has spawned the hospice movement. Our political leaders are making promises much as they did in the mid-1960's with medicare. Some of us wonder when these new promises will be broken. Perhaps when it is discovered that we really didn't save any money.

I mentioned earlier that I did not like what I have seen in our long-term care delivery system. What I see is a very fragmented, confusing, inflexible system which wastes valuable resources that could be used to improve direct services.

The system is fragmented by the many governmental and voluntary providers which are a part of the existing system. Coordination has not even been attempted in any meaningful way. This leads to confusion on the part of consumers, and adds to their problems at a very distressing time in their life. All of this as well as governmental administration of the programs, leads to the waste of valuable resources.

What do I think is needed?

(1) Leadership from someone like you Senator, to help build a coalition between government, providers, and consumers to better coordinate our efforts.

(2) Less regulation where appropriate. Facilities doing a basically good job, should not be continually surveyed and inspected. We operate a 60-bed facility in Mitchell, which has an excellent reputation. Recently this facility was surveyed and inspected 12 times in an 8 month period by various Federal and State agencies. Does this sound reasonable or necessary?

(3) We must produce a uniform assessment procedure for all individuals seeking entrance into a "new long-term care delivery system." This single point of entry into the system would help assure a true assessment of needs and appropriate placement in a cost-effective service. This new long-term care system will include: (1) Inpatient health services; (2) outreach home-delivered services; (3) adult day health care; (4) housing; (5) respite nursing care; and (6) community-based services.

Appropriate placement depends on a mandatory uniform assessment procedure.

Case management is the other essential ingredient of the "new system." Individuals entering the system must be followed with a continued assessment of need so that proper placement can be continued, and needs met as they change.

I am convinced, Senator, that much of this can be accomplished by the provider segment of our existing system, and the result would be a more cost-effective use of the resources now being consumed by health care. In order for this to happen government must spend less time regulating and more time enabling. On the other hand providers must accept new responsibilities, and expand their horizons. These changes will only occur with the leadership you and others in authority can provide.

As we move in new directions, I hope that our society is able to make decisions that are not entirely based on financial considerations. We must also remember the contributions made by our elders, and we must, therefore, meet their needs in a meaningful way. Once again your leadership will be essential.

I'm sure you may also be interested in knowing that there is a new organization in South Dakota, which represents not-for-profit nursing homes and retirement housing programs. We are the South Dakota Association of Homes for the Aging. We are represented in Washington by the American Association of Homes for the Aging, and would welcome any opportunity to work with you.

Thank you Senator, for this sharing opportunity. If I can ever be of any assistance, you need only ask.

Yours truly,

WAYNE MUTH,
*Vice President for Long-Term Care.*

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